

# **And Baby Makes . . .**

**The Unique Joys and Challenges  
of Nurturing the Next Generation  
in a “Special Family”**

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# Agenda

- Introductions
- Context:
  - History
  - How are the Children Faring
- Challenges and Feelings
  - From Perspectives of Children, Parents, Grandparents, Professionals
  - Video
- Providing Support
  - Principles
  - Approach to Providing Support
  - Tips
- Resources

# People with Developmental Disabilities & Parenthood: A Little History



- 1913 Mental Deficiency Act made marriage illegal for persons with mental retardation
- 1920's – 1950's forced sterilization of many people including those with mental deficiencies
- Recent movies: I am Sam, Profoundly Normal, Riding the Bus With My Sister

# How Many Families?



- In the United States, more than 8 million families include at least one parent that has a disability
- Of these, it is estimated that approximately 1.4 million parents with cognitive disabilities are raising children under the age of 18.
- Estimates are that 120,000 babies are born in the US to mothers with developmental disabilities each year

# How are the Children Faring

- Nearly 60 years ago, Michelson (1947) showed that parents with learning difficulties could be helped to give their children better care.
- Ability of a parent to provide adequate care for children is not predictable on basis of intelligence alone (Booth & Booth, 1993, Field & Sanchez, 1999)
- With support and services, risks are reduced and safety and well-being is promoted (Hayman, 1990, Tymchuk & Feldman, 1991, 1994, 1999)
- Research demonstrates that many children in these families go on to lead healthy, normal lives (Booth & Booth 1998)
- Parents are more successful when not having to cope with other external pressures in their lives such as homelessness, harassment, etc



When you Hear the News that your  
Adult Child with a Disability  
is about to become a Parent ~ You Feel:



- Out of control
- Overwhelmed
- Angry
- Confused
- Scared
- Excited
- Worried
- And . . . . .

# Challenges Identified by Professionals

- Planning, Organizing
- Scheduling, Keeping Appointments
- Understanding basics of hygiene, nutrition, health and safety - beginning with feeding, bathing, diapering
- Managing High stress times of day – morning routine, homework hour, dinner hour, bedtime



# Challenges Identified by Professionals, cont



- Reading infants cues, learning their signals
- Adjusting parenting approaches to child's development
- Problem solving – anticipating situations and predicting outcomes
- Setting limits and following through

# The Biggest Challenges: From the Children's Perspectives

- I have above average intelligence but it continues to be a struggle to feel normal
- I am my mother's "mother" - It was like who am I? Am I Laura or my mum? It was like I'd lost my identity.
- From an early age I knew my mum was different from other mums. My mum didn't behave like other mums.
- I remember being 5 or 6 and thinking it was "cool" to have a mom just like me. By 10 it bothered me and in my teenage years I totally took advantage of her.



# The Biggest Challenges: From the Children's Perspectives, cont



- I helped my mum by cooking and cleaning for her. I also helped her to understand things and remember things as she wasn't a very good reader and if she could read it she couldn't understand what it meant. Because of this, when I was 14, I had to take charge of running the house and paying bills.
- I thought I was all alone
- I feel guilty about being ashamed of my mother

# More Voices of the Children

- I know my mother loves me unconditionally even when she cannot understand or help me with the problems I face
- I was born to mentally retarded parents and still feel I had an intellectually fulfilling life. I do not feel I missed out on anything by being raised by my handicapped mother.
- If anything so-called "normal parents" need to take a step back and learn from "retarded" parents.



# The Biggest Challenges: From the Parent's Perspective



- It can be frustrating and you get unsure at times. It would be helpful to have someone to call when we felt lost

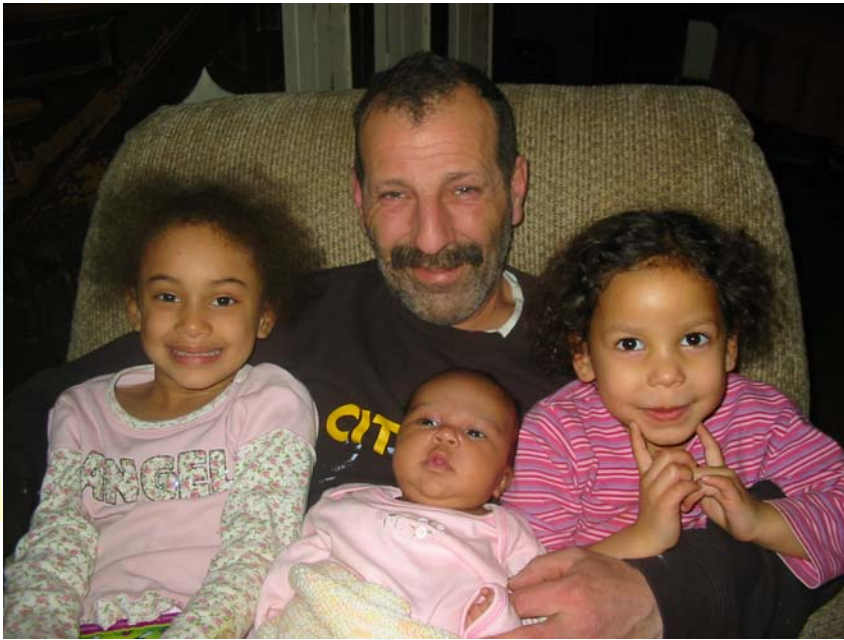
- Its OK to go find resources and use resources offered to you – it doesn't mean you are a failure
- **No one was there for ME, it was always people for the kids, but I needed support too.**
- I feel like its not my child anymore, they have taken over my life.

# From Parent's Perspective, cont

- When somebody listens to me, I am a better mom – that's what parenting is about, finding people who can help you do it when you're not sure what to do.
- Sometimes I get stressed and I think I can't cope, but then I listen to music or have a long bath. Its good to be a mum.
- There are things you can't talk about with somebody who hasn't been there. That's why we need our own support group
- I like being a mom but it is stressful. Sometimes I don't know what to feed them and how to dress them and I worry all the time.
- Don't give up



# The Biggest Challenges: From the Grandparents or Siblings Perspective



- My daughter says she wants to grow up, get married and have a baby. I never expected her to have those dreams.
- My life is already fully occupied helping my daughter to try to live independently, never mind trying to help raise a grandchild
- What will happen to both of them if I become ill, or die before my grandchild is grown?
- 60% of siblings of adults with MR expect to become primary caretaker in the future, sisters more than brothers

# Providing Support: Guiding Principles

- A parent-child relationship is worthy of support even when the parent cannot meet all of the child's needs
- Parents with learning differences have the same feelings of care and affection for their children as other parents
- People with cognitive limitations CAN be good parents
- Children CAN do well in these families
- Focus on strengths, not weaknesses
- **Support should be given to the family as a unit, not just to the child**



# Balancing Support against Interference



- The Supported Parenting Model
- Competence-promoting support vs. Competence-inhibiting support
- “Be patient. Be alert. Be a guide”  
Donna Thornton

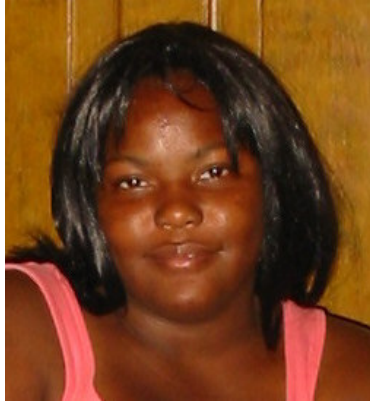
# Balancing Act, cont

- The purpose of support is to help people do things for themselves, not to do things for them
- Do not undermine parents in the handling of their own children



- Attitude is as important as actions – how support is offered and given matters as much as what the support is

# Tips – specific types of support that is helpful



- Help family develop tools for organization – such as a phone list, or feeding schedule, calendar
- Assist with paperwork and organize in binders, folders
- Assist parent in developing questions to ask teachers, doctors, etc
- Don't work on too many goals at once

# More Tips

- Provide information in bite-size increments. A parent of a baby does not need to worry about helping her child with homework yet.
- Sometimes the parent just needs a friend – someone to talk & listen to
- Use Modeling and practicing more than “teaching” and instructing





# Resources

- Supported Parenting Website:  
[www.supported-parenting.com](http://www.supported-parenting.com)
- Positive Parenting Program at MA ARC:  
<http://www.arcmass.org/>
- This is a support and discussion group for people who have a mentally handicapped or retarded parent or parents. It is a place to share your story, get advice, or help others in a similar situation.  
<http://groups.yahoo.com/group/ourotherlives/>
- Parents with Disabilities online  
<http://www.disabledparents.net>

# And Baby Makes . . . . More A Bigger Family . . . . . More Hopes, More Dreams, More Challenges, More Joys, More Stress, More Love, More Giggles, More Hugs



